The Cystic Fibrosis Affiliate Center of the Hudson Valley

Annual Care Planner

Age: 0-11 years old

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CYSTIC FIBROSIS ANNUAL CARE RECOMMENDATIONS

Year: _____

Name: _____ Date of Birth: _____

Things to do:

- □ Annual lab work
- □ Annual oral glucose tolerance test (if applicable)
- □ DXA scan (if applicable)
- □ Annual pulmonary function test
- □ Annual chest X-Ray
- □ Annual acid fast bacillus (if applicable)
- □ Sputum cultures (4 per year)
- □ Annual visit with Nutritionist/Dietitian
- □ Annual visit with Respiratory Therapist
- □ Annual screen for depression & anxiety (if applicable)
- □ Annual visit with Social Worker/Mental Health Coordinator
- □ Complete the Patient Annual Demographic Form
- □ 4 spirometer readings per year (in-office or with home spirometer)
- □ Abdominal Ultrasound if > 3 years old
- □ Cataract screening (if applicable)

Keep track of your progress below!

Date of Visit	BMI	FEV1	Culture Done

CFF ANNUAL FORM

To be completed by patient/parent

Date: _____/_____/_____

YOUR NAME:

DATE OF BIRTH: | **ZIP CODE**:

EMAIL ADDRESS:

INSURANCE:

What type of Insurance do you have?

☐ Private ☐ Medicare ☐ Medicaid ☐ State special needs program ☐ TriCare/Military
☐ Indian Health Service ☐ Other: _____
☐ No insurance

Are you under a PARENT'S INSURANCE?

☐ Yes ☐ No

Do you receive ASSISTANCE FROM A PATIENT ASSISTANCE PROGRAM?

☐ Yes ☐ No

DEMOGRAPHICS:

BIOLOGICAL SEX AT BIRTH: ☐ Male ☐ Female

RACE/ETHNICITY:

☐ Decline to answer

☐ White ☐ Black/African American
☐ Asian ☐ American Indian or Alaska Native
☐ Native Hawaiian or Other Pacific Islander
☐ Some other race
☐ Two or more races: select all that apply
- ☐ White ☐ Black/African American
- ☐ Asian ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander

☐ Hispanic Origin: ☐ Yes ☐ No

MARITAL STATUS (Age 18 or older):

☐ Single ☐ Living together ☐ Married ☐ Separated ☐ Divorced ☐ Widowed
☐ Decline to answer

EMPLOYMENT (Age 18 or older):

☐ Part Time ☐ Full Time Homemaker ☐ Full Time Employment ☐ Unemployed
☐ Student ☐ Disabled ☐ Retired ☐ Decline to answer

EDUCATION LEVEL:

PATIENT (You):

⬜less than high school ⬜High school ⬜Some College ⬜College ⬜Master ⬜Doctorate
⬜Decline to answer

Patient's Father:

⬜less than high school ⬜High school ⬜Some College ⬜College ⬜Master ⬜Doctorate
⬜Decline to answer

Patient's Mother:

⬜less than high school ⬜High school ⬜Some College ⬜College ⬜Master ⬜Doctorate
⬜Decline to answer

Patient's Spouse:

⬜less than high school ⬜High school ⬜Some College ⬜College ⬜Master ⬜Doctorate
⬜Decline to answer

How many people are in your household, including yourself? _____ ⬜Decline to answer

What is your estimated ANNUAL HOUSEHOLD INCOME?
$_____ ⬜Decline to answer

SMOKING

Did you smoke cigarettes?
⬜No
⬜Yes, less than 1 pack per day
⬜Yes, 1 or more pack per day
⬜decline to answer
⬜Not applicable

Does anyone in your household smoke cigarettes? ⬜Yes ⬜No ⬜Decline to answer

How often are you exposed to secondhand smoke?
⬜Never
⬜Daily
⬜several times per week
⬜several times per month or less
⬜declined to answer
⬜Unknown

VAPING

Did you use electronic cigarettes (vaping)? ⬜Yes ⬜No ⬜Decline to answer

How often did you vape? ⬜Everyday ⬜Some days ⬜Not at all ⬜Decline to answer

IMMUNIZATION

Did you receive the influenza vaccine this year? ⬜Yes ⬜No ⬜Decline to answer

Did you receive COVID vaccine? ⬜Yes ⬜No ⬜Decline to answer

PULMONARY

Do you use OXYGEN? ⬜Yes ⬜No
If YES: ⬜Continuous ⬜Nocturnal and/or with exertion ⬜During exacerbation ⬜As needed

Do you use any NON-INVASIVE VENT? (assisted breathing, BiPap, CPAP, etc): ⬜Yes ⬜No

Did you have a CHEST X-RAY this year? ⬜Yes ⬜No

EYE CARE

Did you get checked for cataracts this year? ⬜Yes ⬜No ⬜Unknown

If you have diabetes, did you have a retinal exam done by an ophthalmologist?
⬜Yes ⬜No ⬜Unknown ⬜Not applicable

PREGNANCY:
⬜Not applicable

Are you or were you PREGNANT this year? ⬜Yes ⬜No ⬜Decline to answer
If YES, date of last LMP: _____/_____/_____
If YES, outcome of pregnancy:
⬜Live ⬜stillbirth ⬜spontaneous abortion ⬜therapeutic abortion ⬜undelivered
⬜decline to answer
Date of outcome: _____/_____/_____

IF AGE 2 YEAR or LESS:
⬜Not applicable

Did your child attend DAYCARE this year? ⬜Yes ⬜No ⬜Unknown
Did your family receive genetic counseling this year? ⬜Yes ⬜No ⬜Unknown
Was your child given SYNAGIS this season (Sept - Jan)? ⬜Yes ⬜No ⬜Unknown

Please return completed pediatric patient forms to:	Please return completed adult patient forms to:
New York Medical College Attn: Boston Children's Health Physicians Dr. Elizabeth de la Riva-Velasco 40 Sunshine Cottage Rd Skyline 1NE29 Valhalla, NY10595 Fax: (914)614-4261	Dr. Timothy Collins 21 Reade Place, suite 1000 Poughkeepsie, NY 12601

CF Affiliate HVNY 1.26

CF ANNUAL NUTRITION SCREEN
PEDIATRIC (0-11 years old)

Patient name_____Date_____

Name of person filling out this form_____

TO BE COMPLETED BY PARENT OR GUARDIAN:

1. Have there been any bone fractures, broken bones, or falls in the past year?
   - ☐ Yes, Explain: _____
   - ☐ No

2. Has there been excessive or increased bruising in the past year?
   - ☐ Yes, Explain: _____
   - ☐ No

3. Has there been any of the following changes to bowel function in the last 6 months? Indicate all that apply:
   - ☐ Increase frequency
   - ☐ Decreased frequency
   - ☐ Loose stools
   - ☐ Hard stools
   - ☐ Abnormal/Foul smelling stool
   - ☐ Color changes in stool
   - ☐ Other _____
   - ☐ None

4. There is not enough food in the home to feed your family

   Often true ___ Sometimes true___ Never True____

5. It is difficult to afford supplements, vitamins, formula, or tube feeding supplies

   Often true ___ Sometimes true___ Never True____

6. Please indicate which of the following are true for your child in the last week:
   - ☐ Eating more than usual
   - ☐ Eating less than usual
   - ☐ Eating the same as usual

7. Which of the following weight trends apply to your child most recently?
   - ☐ Weight gain
   - ☐ Weight loss
   - ☐ No weight change
   - ☐ Other: _____

8. Please indicate which of the following are true for your child in the last month:
   - ☐ Increased energy, activity, or exercise
   - ☐ Decreased energy, activity, or exercise
   - ☐ No changes in energy, activity, or exercise

Thank you for completing this survey!

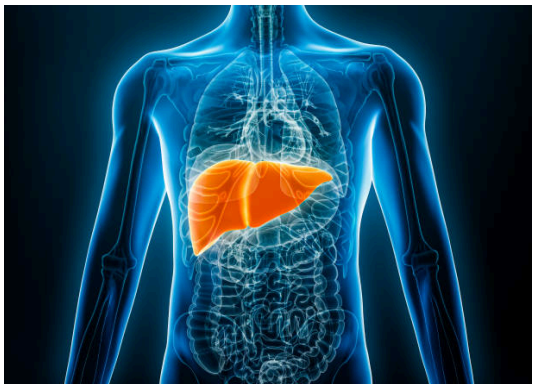
If you have any questions, concerns, or topics you'd like to discuss with your dietitian please list them below or call 845-214-1850 to make an appointment in person or via telehealth!

_____
_____
_____
_____
_____
_____
_____
_____

Cystic Fibrosis and the Liver
Liver and Spleen Ultrasound Screening

The liver is one of the vital organs of the body. It has over 500 functions that keep the body working properly. These liver functions include:

- Making bile which helps break down fats during digestion. The bile is stored in the gallbladder.
- Converting excess blood sugar (glucose) into glycogen for storage to be used as needed, helping to keep blood sugar balanced.
- Regulating blood levels of amino acids, which are the building blocks of proteins.
- Regulating blood clotting to prevent abnormal bleeding or clotting.
- Processing hemoglobin in red blood cells for its iron content (the liver stores iron).
- Clearing bilirubin from processed red blood cells. Bilirubin build-up turns the skin and eyes yellow.
- Making immune factors to fight infection and removing bacteria from the bloodstream.



People with cystic fibrosis may develop liver problems that keep the liver from performing its many functions properly. For example, in people with cystic fibrosis, the bile can become so thick that it makes gallstones. CF can also cause the liver to become stiff and raises the blood pressure within the liver and the spleen.

The best ways to detect any changes to liver health are:

- Regular doctors visits for physical exams.
- Blood tests to screen for any changes in liver functions.
- Ultrasound to screen for any changes in the liver, gallbladder and spleen.

The ultrasound of liver, gallbladder and spleen does not involve any radiation and does not require any special preparation. The Cystic Fibrosis Foundation recommends a screening ultrasound of the liver, gallbladder and spleen every 2 years for children from age 3 to 18 years. Adults with CF should have at least one baseline screening ultrasound.

A prescription for screening ultrasound of liver, gallbladder and spleen will be provided by your CF doctor. The ultrasound can be scheduled at any of the following imaging facilities:

Vassar Brothers Medical Center	Scheduling: 845-790-8855
WMC-Mid-Hudson Regional	Scheduling: 845-431-8776
WMC-Valhalla Advanced Imaging Center	Scheduling: 914-493-2500
MD Imaging	Scheduling: 845-471-2848

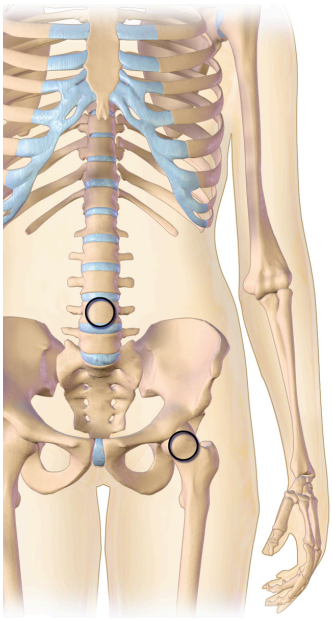
For additional information on CF associated liver disease, speak with your CF physician or visit CFF.org.

Cystic Fibrosis (CF) and Bone Health

How Does CF Affect the Health of Your Bones?

Since people with CF can have low bone minerals, they are at risk for osteopenia and osteoporosis. In CF, it can happen at any age but becomes more common in the later teen and adult years. This causes brittle bones and can lead to pathologic bone fractures.

Osteopenia: Bones do not have enough minerals



Normal bone

Osteoporosis

Osteoporosis: Holes in the bones are too big

Pathologic Bone Fractures: A break in the bone that was not caused by force or impact.

Contributing Factors to Bone Disease:

- Low BMI or weight
- Pancreatic insufficiency
- Calcium, Vitamins D, or Vitamin K deficiencies
- Lung infections and low FEV1
- Steroid use
- Physical inactivity
- Advancing age
- History of fracture(s)
- Delayed onset of puberty

How to Keep Your Bones Healthy:

Maintain healthy BMI & weight	Maintain normal calcium, vitamin D, and vitamin K levels	Incorporate weight bearing exercises
Follow up with your registered dietitian annually	Complete routine lab work and recommended DEXA scans (bone density scans)	Complete quarterly physician visits

What is a DEXA Scan?

DEXA (or DXA) stands for Dual-Energy X-Ray Absorptiometry. This radiology test uses a small amount of x-ray to look at the mass and density of bones.

Why Do I Need a DEXA Scan?

DEXA scans are used for screening purposes to evaluate your bone health and bone density. For people with CF, it is recommended that they have an initial scan at age 18, unless otherwise recommended by their physician.

How Long Does the Scan Take?

20 minutes.

Do I have to Prepare for the Test?

No. There is no preparation needed.

Where can I get the Scan?

Vassar Brothers Medical Center	**Scheduling: 845-790-8855**
WMC-Mid-Hudson Regional	**Scheduling: 845-431-8776**
WMC-Valhalla Advanced Imaging Center	**Scheduling: 914-493-2500**
MD Imaging	**Scheduling: 845-471-2848**

What Happens with My DEXA Scan Result?

Your CF physician or dietitian will review results with you and provide follow up recommendations and/or interventions.

CFTR Modulators and the Eyes

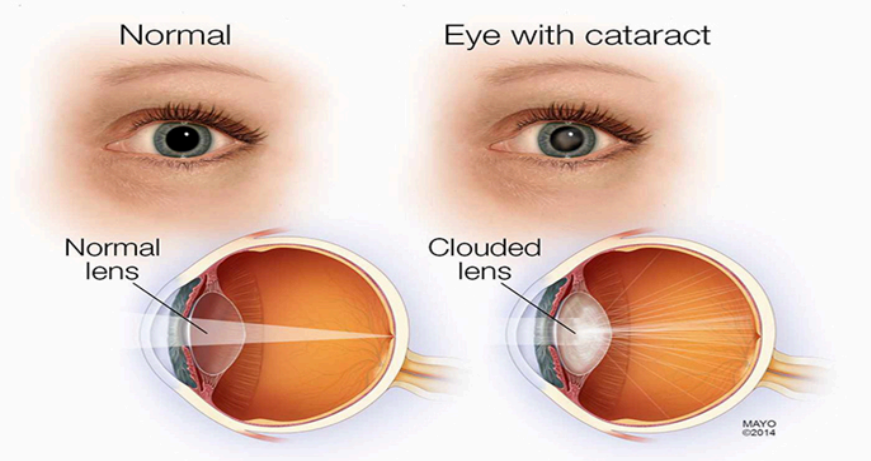
What are CFTR Modulators?

Cystic fibrosis transmembrane conductance regulator (CFTR) modulators are medications designed to correct the malfunctioning protein made by the mutated CFTR gene. Because cystic fibrosis (CF) can be caused by many different CFTR mutations, there are currently five CFTR modulators for people with certain mutations:

- Alfytrek (vanzacaftor/tezacaftor/deutivacaftor)
- Trikafta (elexacaftor/tezacaftor/ivacaftor)
- Symdeko (tezacaftor/ivacaftor)
- Orkambi (lumacaftor/ivacaftor)
- Kalydeco (ivacaftor)

What are Cataracts and What are the Symptoms?

Cataracts are a clouding of the lens of the eye, which is normally clear. This can make it more difficult to see over time. Some symptoms include sensitivity to bright lights, having difficulty seeing at night, blurry vision, double vision, seeing bright colors as faded or yellowed.



How can CFTR Modulators affect Cataracts?

Most cataracts develop due to aging, but CFTR modulators can also cause cataracts. The exact way of how CFTR modulators cause cataracts is unknown at this time. Studies have shown that a small percentage of patients on ivacaftor can develop cataracts within a few years of starting treatment. This is known as ivacaftor-associated or ivacaftor-induced cataracts. As more patients get on modulator treatments, the association between modulators and cataracts will become more clear.

How are Cataracts Diagnosed?

Cataracts are diagnosed with a comprehensive eye exam that looks for any abnormalities to the lens and other parts of the eyes.

I am on a CFTR Modulator. When should I get checked for Cataracts?

Ideally, an exam to screen for cataracts should be done prior to starting CFTR modulator therapy. Once on a CFTR modulator, a yearly eye exam is recommended. Talk to your CF physician about getting a referral to an ophthalmologist (a medical doctor who specializes in care and treatment of the eyes) if you are already on a CFTR modulator and have not had an eye exam, or if you are eligible for a CFTR modulator and are considering starting treatment.

References
CFTR Modulator Therapies | Cystic Fibrosis Foundation
What Are Cataracts? - American Academy of Ophthalmology
Ivacaftor-induced Cataracts in Patients with Cystic Fibrosis - EyeWiki

School's Guide to Cystic Fibrosis

About Cystic Fibrosis

CF is a life-threatening genetic disease. It is **not** contagious and does not affect cognitive ability.

In people with CF, a defective gene causes the body to produce unusually thick, sticky mucus that can clog the lungs, pancreas and other organs. This buildup can lead to severe respiratory and digestive problems that may warrant special accommodations in a school setting.

CF affects each person differently. Some people with CF are in good general health, while others are severely limited by the disease and are unable to attend school regularly. It is important that you meet with your student's parents and CF health care providers to determine the best way to support your student's unique needs.

CF and Nutrition

In people with CF, mucus can obstruct the digestive system and prevent proper absorption of nutrients, which can slow growth.

To boost growth and nutrition, children with CF take pancreatic enzymes and vitamins. Some children with CF may follow a special diet.

Meet with your student and his or her parents about ways to help your student maintain a healthy diet. Examples of accommodations may include allowing the child with CF more time to eat during lunch, to snack throughout the school day, to carry a water bottle, and to take enzymes with each snack and meal.

Although enzymes help with digestion people with CF may still experience abdominal pain, foul-smelling gas, or diarrhea. This is why it is important to:

- Give a student with CF frequent access to the bathroom.
- Not draw attention to the student if she or he passes gas frequently.
- Make the student feel comfortable about going to the bathroom when needed.

Exercise

Although some people with CF have difficulty breathing and may tire easily, regular exercise is generally encouraged because it helps loosen the mucus that clogs the lungs and strengthen the muscles used to breathe. Exercise also promotes healthy social interaction with peers.

To help determine the appropriate level of physical activity for your student:

-Talk to the student and parents about the activities they are comfortable with.

-Include the student in all games and activities in which he or she is interested.

Dehydration is a real concern for people with CF who are active because they can lose more salt when they sweat than those who do not have CF. During exercise, encourage your student to:

-Drink 6 to 12 ounces of fluid every 20 to 30 minutes.

-Consider sports drinks with added carbohydrates and salt.

-Avoid drinks with caffeine, which can increase fluid loss.

Coughing

People with CF tend to cough a lot to clear mucus from their lungs. In a classroom, a student with CF may feel self-conscious about coughing in front of others. You can help your student feel more comfortable by:

-Making it easy for the student to drink water at his or her desk or slip out of the classroom for water.

-Not drawing attention to the student who is coughing.

-Encouraging your student to keep a box of tissues to cough into and a trashcan to dispose of the tissue near their desk.

-Allowing the student to clean his or her hands with alcohol-based hand gel at their desk.

Infection Prevention and Control

The thick mucus that builds up in the lungs of people with CF allows germs to thrive and can lead to serious lung infections. As a result, people with CF are more vulnerable to getting sick by catching germs from others who are sick, and particularly from others with CF.

The Cystic Fibrosis Foundation's Infection Prevention and Control Guidelines help people with CF, their families, and caregivers reduce the spread of germs in everyday life, including school settings, and provide the following recommendations:

-Keep a minimum 6-foot distance (2 meters) from others with a cold, flu, or an infection in all settings, especially indoors

-Encourage everyone to wash their hands by making soap and water or alcohol-based hand gel readily available in the classroom. Cleaning hands is particularly encouraged after using commonly shared items (such as pencil sharpeners or lab equipment).

-Avoid sharing personal items, such as straws or eating utensils.

-Encourage students to cover their cough or sneeze with a tissue. Throw the tissue away immediately, then wash or clean hands. If a tissue is not available, encourage students to cough or sneeze into their inner elbow.

While lung infections in people with CF pose no danger to the public, they do pose a significant danger to others with CF. If there is **more than one person with CF at your school** (unless they are siblings from the same household), it is **essential** that they keep a safe distance from each other. People with CF should maintain at least a 6-foot distance from each other. They should not sit near each other in class or on a school bus. They should never share water bottles or other personal items.

For additional readings and an informational video on germs, infection control and how students with Cystic Fibrosis can be protected through everyday action and precautions. You may also visit the Cystic Fibrosis Foundation website, or contact Boston Children's Health Physicians to speak with our physicians or staff members.

Help For Your Students and Their Families

Living with cystic fibrosis demands complex care and treatment, which involves navigating a maze of health concerns. Families and students with cystic fibrosis have to go to the doctor multiple times a year for routine follow up, in addition may need lab work, tests and treatments. This may cause the student to miss school, need additional time with assignments and miss some activities. Please refer to the students 504 or IEP plan and reach out to our office for any additional questions or concerns.

Appointment Directory

Laboratory Services:

- Vassar Diagnostics (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- WMC - MHRH Lab (845)483-5917 1 Webster Ave., Suite 204, Poughkeepsie, NY 12601

Diagnostic Imaging Centers:

- Vassar Brothers Medical Center (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- WMC - MHRH Radiology (845)431-8776 241 North Rd., Poughkeepsie, NY 12601

Social Worker & Mental Health Coordinator Appointments (Telehealth available)

- Addison Forgit (914)504-0162 19 Bradhurst Ave, Hawthorne, NY 10532
- Caitlin Lennon (914)504-0166 19 Bradhurst Ave, Hawthorne, NY 10532

Respiratory Appointments (Telehealth available)

- Claudia Salazar, BSRT, RRT-ACCS
  - Telehealth: Email claudia.salazar@nuvancehealth.org
  - In-Person: Vassar Brothers Medical Center, 45 Reade Pl., Poughkeepsie, NY 12601
    - (845)790-8855 Central Scheduling

Dietitian Appointments (Telehealth available)

- Michelle Triolo 845-437-3026 45 Reade Pl., Poughkeepsie, NY 12601
- Lauren Jackson 845-214-1850 Vassar Brothers Medical Center
  21 Reade Pl., Poughkeepsie, NY 12601

Pulmonary Function Tests

- Vassar Diagnostics (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- Westchester (914)493-5491 19 Bradhurst Ave, Hawthorne, NY 10532
- Middletown (845)281-7657 212 Crystal Run Rd, Middletown, NY 10940